



POST POLIO MATTERS

Polio Survivors Network Newsletter - Volume 8, Issue 7/12
n.b. Volumes 1 to 6 published under the name LincPIN.
www.poliosurvivorsnetwork.org.uk

**FEBRUARY
2015**
Vol 8, Issue 7

MEASLES ELIMINATED IN 2000 IN U.S.A.

Feb 2015 - MEASLES RETURNS 120+ IN 17 STATES!

Measles is a highly contagious disease that can lead to croup, diarrhea, pneumonia and encephalitis.

**SPEAKERS
AND
ANNUAL
GENERAL
MEETING**

25.4.2015

LINCOLN

**Main
Speaker**

**ANN
PARKINSON**

**NEURO
PHYSIO-
THERAPIST
Page 11**

A Paralyzing Fear: The Story of Polio in America.

Film review - When There Was No Vaccine

With the anti-vaxxers holding sway among today's stupid set, Nina Gilden Seavey's 1998 documentary *A Paralyzing Fear: The Story of Polio In America*, now streaming on Amazon and Snag Films, is a timely and urgent reminder of the heart-breaking effects of an unchecked, brutal virus.

But the threat is growing again. Pockets of polio exist in impoverished parts of the world, places that are accessible by airplane. And thanks to superstitious, ill-informed, selfish anti-vaxxers and the craven U.S. state governments that permit them to opt out of mandatory vaccinations, a traveler could, within half a day, bring that scourge back to America. ..That history must be seen, and its repetition must be prevented. As one of the interviewed victims says of the vaccine, "For me, it was too little, too late. But I was glad that nobody else would have to go through this."

See the film and vaccinate your kids.

[Excerpted from Harold Itzkowitz, The National Memo, Feb 12th 2015]



WILD POLIO VIRUS TOTALS

	2010	2011	2012	2013	2014	2015
TOTALS	1352	650	223	369	358	7
Wild Polio Virus 1	1265	583	202	369	358	7
Wild Polio Virus 3	87	67	21	0	0	0
In Endemic countries	232	341	217	145	339	7
In Non Endemic countries	1120	309	6	224	19	0
No. of countries	20	16	5	8	9	1

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**END
POLIO
NOW**

Home of the
Lincolnshire
Post Polio
Library



Enter 100+ articles

**Speakers and
Annual
General
Meeting
Saturday
April 25th
10.00 am
To
3.00 pm
North
Hykeham
Memorial
Hall,
Lincoln
LN6 9RY
SEE PAGE 11**

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**NAIDEX
NEC
Birmingham
April 28 - 30
2015**

**Mobility
Roadshow
Donington Park
June 25 - 27
2015**

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**Post Polio
News
ppn
www.post-
polio.org.uk**

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New Members and Donations received.

Thank you to all members who have recently renewed.

Herewith the totals of donations for 2014.

Grants	£ 1500.00
* Members donations	£ 1511.00
Meeting and Conference Fund	£ 1665.00
Donations towards A.G.M.	£ 123.00
Val Scriveners Photo Cards	£ 96.00
Gift Aid	£ 389.00
TOTAL FOR 2014	£ 5,284.00

* Please note that we have been able to keep our annual membership fee of £12.50 per year at that rate for many years thanks to the generosity of members who can afford to adding a donation.

Donations towards our Meeting and Conference Fund allow PSN to pay some of the expenses incurred by our Trustees at Post Polio Conferences and other important meetings.

Thankyou for buying Val Scriveners Photo Cards and ticking Gift Aid..

This publication is provided as a service to those seeking such information and is not intended as a substitute for professional medical care. The opinions expressed in this publication are those of the individual authors and do not necessarily constitute endorsement or approval by the Polio Survivors Network. ALWAYS consult your doctor before trying anything recommended in this or any other publication.

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Editorial by Hilary Boone

It is now 15th February 2015.. Where did January go? They do say that the older you get the faster time goes because you have more experience of time.... I must be getting really old ☺.

This year's flu vaccine is reported to have barely protected people against the main stream of flu being spread in the UK. Evidence shows the vaccine is stopping only three, instead of 50, out of every 100 vaccinated people from developing symptoms.

The World Health Organisation decide in February which strains of flu are expected and one of the three strains they expected to circulate this winter has since mutated. Richard and I have had the flu vaccine every winter but we both suffered badly this winter with eight weeks of flu, coughs and chest infections. Coughing, and that's not easy when you have respiratory insufficiency - are under breathing - to clear the, some infected but, mostly sticky mucous has been tough. Simon Parritt has written us an article 'Don't take your Breathing for Granted'. Any member requiring more information please email/write or ring us.. As most of you know Richard has used a bi-level ventilator at night since 2006 and this extra coughing lead to many more broken nights and increased daily fatigue for us both. I must thank Dave Marris for the garden pot of primroses and hyacinths he brought round a few weeks ago, now flowering, helping me remember that Spring is just around the corner.

I have included information about the End Polio Now campaign in our newsletters hoping one day that no more children would experience the vagaries of polio and to most of us the unexpected sting in the tail of Post-Polio. So far the known figure for the world for POLIO this year is SEVEN in Pakistan, that's nine down on last year at the same time of the year.

There has been a lot of talk recently about the decreasing number of people vaccinating their children in the last decade, leading to new outbreaks of diseases once thought eradicated in that area. E.g. The new outbreak of measles in the USA. See text box on front page.

We all know that Vaccines can prevent outbreaks of disease and save lives. Nearly all our members caught polio before the polio vaccine was readily available where we lived. A few have caught polio from the live vaccine including, as you know, our youngest member Hamish. So whilst it is accepted that there can be a few problems for some with the vaccine, if the number of vaccinated people drops below about 90% then we will see the return of diseases and a huge increase in the number of deaths and people suffering from the after effects.

"Community [herd] Immunity". When a critical portion of a community is immunized against a contagious disease, most members of the community are protected against that disease because there is little opportunity for an outbreak. Even those who are not eligible for certain vaccines - such as infants, pregnant women, or immunocompromised individuals - get some protection because the spread of contagious disease is contained. This is known as "community {or herd} immunity."

Speakers and our Annual General Meeting.

This year we are delighted to say that **Ann Parkinson, a Neurological Physiotherapist** has agreed to do a presentation for us on how a Neuro Physiotherapist can help with our PPS issues. Ann is only available in the morning so we are turning the day around compared with past years. See page 11 for more details.

The North Hykeham Memorial Hall will be open at 10.00 am and to get the widest possible coverage for polio survivors and their family we are inviting the members of the British Polio Fellowship Lincolnshire Branch to join us from then to the start of our Members only Annual General Meeting at 2.00 p.m. I am a member of the University of Lincoln Users and Carers Panel and we hope that some of the Health Students might be able to join us as well.

**Lincoln Neuro Physiotherapy, Lincoln Physiotherapy and Sports Injuries Clinic,
8 Mill Lane, North Hykeham, Lincoln, LN6 9PD**

www.lincolnneurophysio.co.uk - Tel: 01522 688699

MESSAGE FROM OUR CHAIRMAN - Simon Parritt

I have written a piece about Breathing starting on next page and the rest of my message is important information from the Neurological Alliance. **“We must be invisible no longer.”**
www.neural.org.uk

The Invisible Patients: Revealing the state of neurology services - 2.1.2015

The Neurological Alliance is delighted to announce the launch of its new report, *The Invisible Patients: Revealing the state of neurology services*. Bringing together the findings of the Neurological Alliance’s inaugural quality of commissioning audit and neurological patient experience survey, the report identifies significant variation in the quality of the commissioning of neurological services among clinical commissioning groups (CCGs). Findings include:

- Only 14.7% of CCGs have assessed local costs relating to the provision of neurology services
- Only 20.4% and 26.2% of CCGs respectively have assessed the number of people using neurological services and the prevalence of neurological conditions within their area
- Only 33% of CCGs obtain vital feedback from patients in regards to the neurological services they commission
- These issues have a significant impact on patients’ care, with 58.1% of patients having experienced problems in accessing the services or treatment they need.

In response, *The Invisible Patients* sets out a number of recommendations including:

- Every CCG should collate up to date and accurate local neurology data, underpinned by routine and rigorous assessments of the prevalence of neurological conditions and of the number of people using neurological services locally
- All CCGs should ensure that mechanisms are put in place to encourage and capture patient feedback and input in regards to the quality and development of local neurology services
- CCGs should work in partnership to identify clinical and research trial opportunities locally and support the appropriate sharing of information on such opportunities with patients

Commenting on the report, the Neurological Alliance’s Chief Executive, Arlene Wilkie, said:

“For too long, people living with neurological conditions have been the ‘invisible patients’, often marginalised by a system that doesn’t understand their conditions or their needs. This has to change. I am delighted that this report provides a vital first step in exposing the true state of neurological services today. It is time for the health and care system to open its eyes to the needs of the millions of people who live with these complex and challenging conditions. **They must be invisible no longer.**”

The report, and the supporting patient experience survey and CCG commissioning audit datasheets can be found on the Neurological Alliance website.

www.neural.org.uk/updates/245-invisible%20patients%20variations%20report

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Chartered Psychologist, HCPC Registered Counselling Psychologist

www.sp-psychology.com

Simon Parritt <simon.parritt@poliosurvivorsnetwork.org.uk>

[Editors note: I checked the Data and there were few statistics provided by the four Lincolnshire CCG’s. For 16 years, members of Lincolnshire Neurological Alliance, have asked Lincolnshire NHS ‘How many patients have each neurological condition’ to support our campaign for better services. How can they plan neuro services if they still do not know how many need them?

Post Polio Syndrome - Written by U.K. Doctors for Doctors
www.patient.co.uk/doctor/post-polio-syndrome

DON'T TAKE YOUR BREATHING FOR GRANTED

From Simon Parritt, Chair of Polio Survivors Network.

I must point out that I am not a doctor, but a psychologist and anything I say is based only upon my experience as someone who was completely paralysed with bulbar polio in January 1956 at the age of 5. I spent some months in an iron lung, being tube fed, having lost all breathing and swallowing ability. After just under 2 years in hospital, I returned home and, although my upper body and arms recovered less well, I was able to walk independently and attended normal school, until spinal curvature and pain prevented me at the age of 16. After an extensive spinal fusion in 1968 at the RNOH in Stanmore, I spent four years at art school, which was in hindsight my maximal recovery period. Despite being fairly independent I was still left quite physically impaired, so unlike many who were left with one area of paralysis or even complete recovery, I think this protected me from overdoing it, though some of my family might disagree!

The impact on me of beginning full time work was perhaps greater than I, or others, expected and I started to have increasing odd health and fatigue problems. They were thought of by most as psychological in origin, and I was at one point given anti-depressants by a neurologist (which went in the bin). I eventually, after making a fuss and discharging myself at one point, managed to get a reluctant referral to the amazing Dr. Geoffrey Spencer, at what was then The South Western Hospital, which was the origins of what later became The Lane Fox Unit. I became involved as a regular patient in 1975 and later part of their patients association committee. I was lucky to have been involved at the Lane Fox early in my life and I think this may have protected me as I always had somewhere to go. Whilst not always being perfect they were, and despite their expansion and involvement in other areas, still are nearly always ready to listen and work with you in a co-operative and patient centred way to find a solution. I was lucky to have learnt so far back in my life that everything, health wise is impacted by polio and that my doctors and I ignore the interaction at my peril.

I have been on night ventilation since 1998 under the care of the Lane Fox and am currently, once again after many years break, a member of the Lane Fox Patients Association committee. After working as a designer and artist full time until my mid 30s I retrained as a psychologist and psychosexual therapist and managed to tailor my work to my physical abilities and been lucky enough to work in many fascinating areas with other disabled and health professionals including geriatric medicine, general practice and the voluntary sector. I currently work as a counselling psychologist in independent practice as well as teaching and writing around the psychology of disability and chronic illness amongst other mainstream psychology issues.

Breathing.

One of the major concerns that arise as we age is breathing. If your breathing was affected in the initial stages or you were in an iron lung, you are at risk of developing breathing problems later in life. However, although in the initial recovery period it may have seemed that only a few muscles were affected, we now know this may not be true. Whilst you have noticeable and residual problems in one area, there are likely to be more areas affected but they remained functioning. It therefore follows that anyone who had polio may experience weakness or loss of function in any part of the body, including the respiratory muscles. Therefore, normal muscle loss with aging has a much greater impact upon people who had polio, because they start from a lower level of functioning muscle capacity, so any loss can be critical and cause loss of function.

What to look out for?

If you begin to experience problems of breathlessness, tiredness, daytime sleepiness and feeling unwell or having headaches on waking and a sense that you haven't had a good nights rest, you may be having respiratory problems. Your GP will try to work out what is the cause. Unfortunately the symptoms can also be common issues in ageing and general health that are not specific to polio and the respiratory consequences of having had polio. Indeed, polio people may be treated for heart disease, asthma and other conditions, without also looking at breathing and respiratory

issues relating to polio. Of course it maybe that you have heart problems AND polio breathing problems, but treating one and missing the other will not help you much!

What you should know

When you start to breathe less well it may be only when you are asleep and or lying down. You may not notice it, but slowly your body begins to have trouble getting enough oxygen. When the GP looks at your oxygen levels they may look absolutely normal (for instance one of those finger probes that shows a percentage of oxygen through your skin, pulse oximeter). However, that is not a sufficient test. Your respiratory system may not be working well at night or when lying down, but fine at this point when awake and up and about in the GPs surgery or at home.

Getting coughs and colds will increasingly become more critical for you as you are unable to cough with enough force and will be spending more time lying down, increasing the time you are under-breathing! Of course flu is also an especially serious illness for anyone who has existing problems but especially for us polio people (and remember the flu vaccine is essential but doesn't give any guarantee of protection). As a result you should seek fast expert informed advice when you are ill and ensure polio respiratory insufficiency is understood in your case. It isn't a lung disease, its just you are not breathing deeply enough due to muscle loss, **so just pumping oxygen into you will just make things worse and you could be retaining carbon dioxide. It is important those around you and treating you know these facts..**

What you can do

Is this your problem? Even if you just suspect it, ask your GP to refer you to a specialist respiratory medicine physician. Ideally that should be at a centre that understands polio and post polio respiratory issues, such as The Lane Fox Unit. You need a proper assessment of your respiratory functioning as a polio survivor. Some of our members have not been getting this.

What you need

Of course this varies but the major concern that we have at PSN is that there is a wide variance and also low knowledge in the country around breathing and polio. We want to promote a protocol that is best practice. You might expect to have a range of tests and examinations and a professional assessment of your health and medical history, focussing also on your polio as part of the whole picture. They used to call it holistic medicine.

Blood samples - which is an arterial blood gas and offers insight into breathing, not just at that moment, but evidence of your general breathing efficiency over the recent past as well.

It would also be best to have an overnight test, which doesn't just look at just your finger oxygen (SpO2) but your carbon dioxide levels when in different stages of sleep and rest. Some units will offer a full sleep study, which also would include other tests, which may include:

- ◆Rapid eye movement (REM) sleep.
- ◆Non-rapid eye movement (NREM) sleep.
- ◆Air flow in and out of your lungs as you breathe
- ◆The level of oxygen in your blood
- ◆Body position
- ◆Brain waves (EEG)
- ◆Breathing effort and rate
- ◆Electrical activity of muscles
- ◆Eye movement
- ◆Heart rate

GETTING IT RIGHT

It can be hard to always get exactly what you need but a good relationship with your GP is worth its weight in gold. However, they need to know what is going on with you. They are not psychic

and cannot know everything especially around polio and post-polio and busy GP's do not have the time to research everything. It is up to you to inform them of what you know by getting to know as much as possible so you can help them to help you.

Muscles of Respiration

Brief Definition - In the process of ventilation, muscles move the lung and chest wall for inspiration and forced (non-passive) expiration.

The Long Description - The Muscles of respiration can be divided into those used during inspiration and expiration.

Inspiration

- **Diaphragm** - Thin, dome-shaped sheet of muscle inserted at the lower ribs. Contraction of the diaphragm moves the abdomen downward and forward increasing the vertical dimensions of the chest cavity. The ribs are also lifted outward increasing the diameter of the thorax. In normal tidal breathing, the diaphragm moves about 1cm (may move up to 10cm during forced expiration). Paralysis of the diaphragm causes *paradoxical movement* in which it moves *up* rather than *down* with inspiration. This occurs when a person sniffs. [The diaphragm has two domes]
- **External Intercostal Muscles** - Connect adjacent ribs and under contraction, the ribs move upward and forward. Paralysis of the intercostal muscles does not seriously affect breathing because the diaphragm is so effective.
- **Accessory Muscles of Inspiration**
 - *scalen muscles* - Elevate the first two ribs
 - *sternomastoids* - Raise the sternum (may contract vigorously during exercise)
 - *alae nasi* - Flare the nostrils
 - *Other small muscles in the neck and head*

Expiration (Non-Passive Only)

- **Muscles in the Abdominal Wall** - Contract forcefully during coughing, vomiting, and defecation.
 - *rectus abdominus*
 - *internal and external obliques*
 - *transversus abdominus*

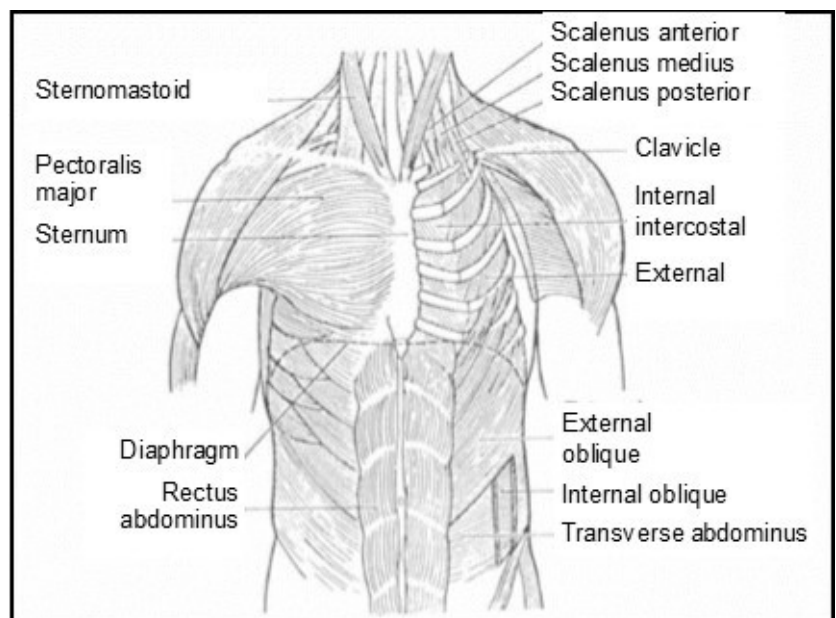
- **Internal Intercostal Muscles** - Pull ribs downward and inward (opposite to external intercostal muscles)

It is crucially important that all these muscles work together in coordination.

LincPIN Volume 5, Issue 9, June 2006 is our largest newsletter of 28 pages based on Respiratory Issues.

<http://www.poliosurvivorsnetwork.org.uk/lincpin5-9.pdf>

Scanlan, CL, et al. (1989). Egan's Fundamentals of Respiratory Therapy.



“In search of a knee support” from Member Zsuzsanna Snarey

I have been aware of the fact that the condition of my right knee was deteriorating and giving me pain for several years now. I went to see my GP over twenty years ago when he sent me for an X-ray which diagnosed decreased meniscus on one side suggesting arthritis. In 2010 Dr Robin Luff suggested knee stabilisation using a Chinese method which I was not very keen on. I have seen knee operations for polio survivors that were unsuccessful. I was advised to see a physiotherapist who prescribed exercises.

In spite of this treatment the knee started to hyperextend more and more and now it is painful after a few minutes of walking. So I started to walk less and less. I already have a UTX Swing calliper for my right leg to control the hyperextension and when I took my calliper for refurbishment to the Orthotist in the summer of 2013 I asked him if he had any suggestions how to support the right knee. He advised me to go to my GP who referred me to an orthopaedic surgeon and when I saw him in July 2014 he recommended a UTX Swing for my right leg. He asked me to come back in six months to show him my calliper. But the Orthotist would not cooperate because in his experience no one had two callipers, one on each leg. I have contacted Nils van Neerдам at Ambroise, manufacturers of UTX Swing callipers, [www.ambroise.nl] who emailed me five videos showing such cases and I have forwarded these to the Orthotist him but it had no effect in convincing him, mainly because he said UTX Swing callipers were too expensive. According to his recommendation I was referred to the local physiotherapy department and waited. Finally getting impatient I contacted my usual physiotherapist in May who sees me for a few weeks every year in Margate and he arranged to see me. He wrote a letter to refer me to The Hospital for Neurology and Neurosurgery in Queen Square London and I had an appointment in October to see Professor Henry Houlden who also agreed that I needed support for the right knee and referred me to their physiotherapist and Orthotist but warned me that there was a long waiting list. I was eventually seen this month, February 2015, one and a half years after I first asked for help but several years after I have started to experience problems!

The physiotherapist at Queen Square offered to write a letter in support of my claim agreeing with me that I needed support for my right knee in the form of a UTX Swing calliper.

I almost feel that I have been pushed from pillar to post to make me wait until I will not need any support to walk because I will be in a wheel chair.

zsuzsi.snarey@gmail.com [Author of Escape from Communist Hungary]

[Editors note:- http://rslsteeper.com/products/orthotics/products1/ambroise_products At least three members have Ambroise Utx swings, and at least one has had two for some years.]

DIFFICULTIES WITH MEDICAL APPOINTMENTS & HOSPITAL WARDS NOT INITIALLY DIRECTLY POLIO RELATED.

Have you visited another medical department, hospital ward or dentist not initially directly related to your polio and had issues?

Have you said, ‘I had polio and will/might have problems with some of the treatment or medications you are suggesting’ and your offered information is either ignored or not taken seriously. The added stress of this to polio survivors [and others with long term conditions] and their carers is way too high and incorrect diagnoses, advice, treatment, operations, medication, therapy levels, etc have cost the NHS more financially and this needs to be addressed.

We need your help if we are to take these issues up with NHS departments to find out how we can provide our information so that it is accepted and taken on board at the earliest point in time.

If you have, will you please tell us more, either write or email or ring the Charity Line during the day if you are unable to do the other two easily.

“Final Act” from Member Dot Ives.

I owe my life to the NHS and will remain forever grateful and thankful. From being born very prematurely in 1955, through polio and corrective surgery when aged 8 – me and my right leg are a walking, if aching, limping, painful testimony to that service.



Fast forward through the years via hysterectomy, lumpectomy, lymphectomy, smashed left ankle to the ongoing saga that is my 'bad back', sciatica and bulging discs (formerly known as slipped discs)..... not forgetting arthritis and Post Polio Syndrome

Scene 1 of this vignette or farce has been played out over the last 5 years..... here followeth the Final Scene....

Characters: PPS (Dot in disguise as) Passive Patient Sufferer

NR: Nice Registrar and

GC: Grand Consultant

Setting the scene:

5 Cortizone injections into spine worked a little but not a lot! Discs still bulging but not as much, pain in right hip is arthritis and will need a hip replacement in the future.

Continuing discussion with Nice Registrar over the last 18 months appears to be concluding that surgery the only option. (Yes, we have discussed and I have explained difficulties and concerns re PPS and general anaesthetics) .

On computer screen is x-ray of hip and at press of a key MRI of my spine.

GC: (enters stage left) Nice to meet you again Dorothy (my Sunday name noted)

PPS: (smile and nod and shake hands)

NR to GC: As you can see the discs are still bulging and surgery has been discussed.....

GC: (peering at computer screen, flitting and flicking between scan and x-ray evidence) Mmmmm

NR: (notices the Mmmm .hesitant reaction, then interjects) “She is really struggling at work”

GC: (not listening) “Not straight forward – not clear if pain in your leg is from polio or sciatica or arthritis,... you will need hip replacing and disc surgery,... Oh, you are still working?”

PPS: (nod and opens mouth to speak)....

NR: (interrupts) “Yes, full time, but really struggling as. her job involves bending and sitting with small children, and her knees are bad also....”

GC: “Ah! But if you are managing to work you are obviously managing. We will delay the surgery for a while. (goes to shake my hand) “Refer back in via GP when need to” (shakes my hand then speedily exits stage right)

NR: (looking embarrassed) “Ah!”.. (shakes my hand also and attempts to leave)

PPS: “Can I ask, I don't use walking sticks unless I am really bad should I use them more often or regularly?”

NR: “Oh no, difficult that.....

For your sciatica – *stick needs to be on same side.

For your hip needs to be on the other side so will need two sticks and that will cause problems with the arthritis in you hands and arms and your PPS – I wouldn't bother if I was you!

*Note: could be the other way round – I was too confused!



“Cod Liver Oil” from Member Vivien Holland, DNN (Diploma in Natural Nutrition)

With such a lot of colds and flu doing the rounds, I'd like to tell you why we take Cod Liver Oil, but where do I begin? I know, I thought, I'll google "Vitamin A". The very first website to come up was:-

<http://www.nhs.uk/Conditions/vitamins-minerals/Pages/Vitamin-A.aspx>

and there was the info I wanted to share with you, with the following bullet points . . .

- 1. Strengthening immunity against infections,**
- 2. Helping vision in dim light,**
- 3. Keeping skin and the linings of some parts of the body, such as the nose, healthy.**

The above article makes reference to Vitamin D too, and we do take an additional supplement of that, as, for us, the amount in cod liver oil is insufficient. Vitamin D is known as the "sunshine vitamin" and it would be lovely to get all we need from spending time in the sun – maybe some manage to do this. It would be wise to get blood levels of Vitamin D tested though, but the following article shows just how patchy it is in the UK as to whether your GP will suggest this. It's worth asking though - our GP was very obliging.

<http://www.pulsetoday.co.uk/clinical/more-clinical-/musculoskeletal/vitamin-d-testing-guidance-to-prompt-sea-change-for-gps/20002686.article#.VN9CXYGQGrU>

Many are conscious of taking Omega 3 fish oils these days, so will be pleased to see that Cod Liver Oil also contains good quantities of both EPA and DHA, some Vitamin E too.

Just going back to thoughts on Vitamin A, we're all very individual in our dietary needs, and some may be thinking they get all the Vitamin A they need through focusing on plant sources of beta-carotene (carrots, sweet potato, green leafy veg). However, it seems the body's utilisation of this is variable, as this article from the Westonaprice.org website shows:

<http://www.westonaprice.org/health-topics/abcs-of-nutrition/vitamin-a-vagary/>

So far this winter we've escaped colds and flu, but we don't kid ourselves that we're invincible – far from it! Just wanted to share this "food for thought".

vivienholland@ntlworld.com

Care Quality Commission

The independent regulator of health and social care in England
Check out your local Hospitals, GP Surgeries, Care Homes and more...
www.cqc.org.uk/content/our-new-inspection-model#reporting

REMINDER FOR MEMBERS

Have you changed your home or email address or phone number recently?

Did you let us know?

Have you told your family and friends you are a PSN member so they can let us know if you move, become ill or go into hospital?

If you do not have internet access, or you do but you are unable to find what you are looking for, and you would like to learn more about any of the articles included in this or any other post-polio newsletter then give us a ring to see how we can help.

01522 888601 (leave a message if there is no-one available to take your call)

POLIO SURVIVORS NETWORK
SPEAKERS [OPEN TO NON MEMBERS] and ANNUAL GENERAL MEETING
SATURDAY APRIL 25th 2015

10.00 am to 3.00 pm.

North Hykeham Memorial Hall,

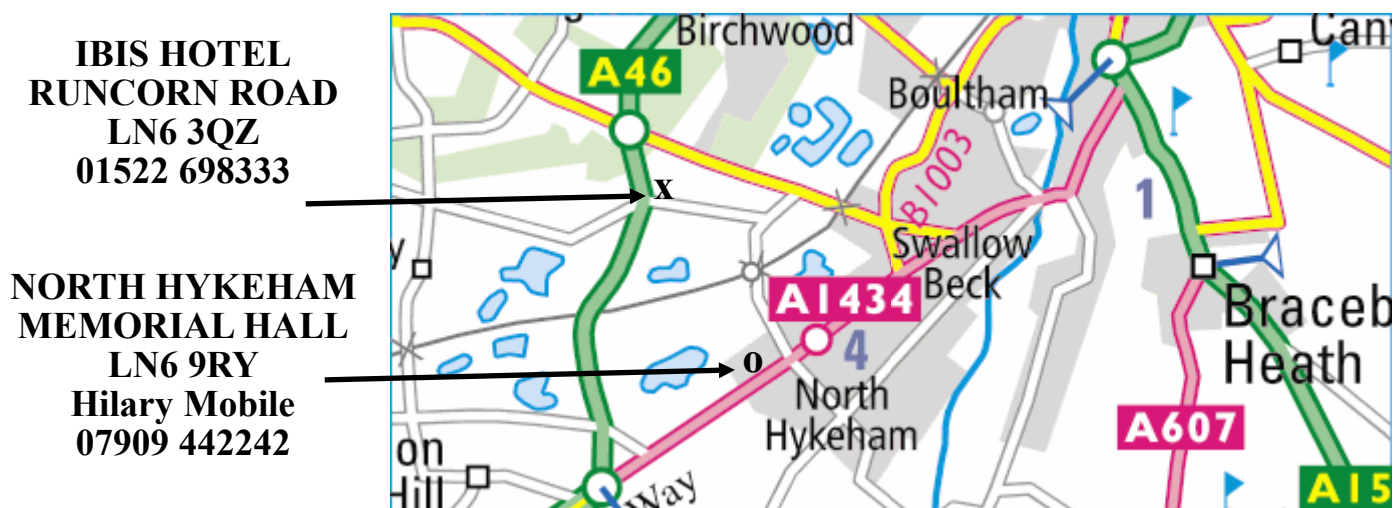
317 Newark Road, North Hykeham, Lincolnshire, LN6 9RY

- 10.00 am. The North Hykeham Memorial Hall on the south western edge of Lincoln will be opened at 10.00 am with half an hour to arrive and have a drink.
- 10.30 am. I will then give the presentation that I gave at the 2nd European Polio Conference in Amsterdam last June with a few additional slides. The title is Painting the Same Picture can Provide Better Clinical Outcomes and we certainly all want better clinical outcomes than most of us have had for years. I hope you will find the information helpful.
- 11.00 am Ann Parkinson, Neuro Physiotherapist will then give her presentation on how Neuro Physiotherapy can help us with our post polio issues. I have been a patient of Ann's for 3 months with considerable improvement in some areas. Neuro assessment and treatment is different from the physio assessments of my past.
- 12.00 pm Maud Berneburg, Holistic Therapist, massage, reflexology, aromatherapy, Reike. Home visits, Lincoln area. Intouchholistictherapies.com
- 12.30 pm Buffet Lunch and plenty of time to chat.
- 2.00 pm Annual General Meeting for Polio Survivor Network Members and any family member, friend or carer with them.
- 3.00 pm Close of event.

As in previous years a few polio survivors [Hilary and Richard, Dot and Husband, Barry Branston and maybe others will be staying locally in the Ibis Hotel marked as an X on the Friday night. Anyone who would like to join us for a meal and/or drink during the evening please get in touch. IBIS is about three quarters full as I write so please contact direct if you want to book a room.

X marks the Ibis Hotel, **RUNCORN ROAD, OFF WHISBY ROAD, LN6 3QZ - LINCOLN. TEL : 01522 698333**
Going north up the A46 Green road [Lincoln Bypass] turn right off the A46 at a new roundabout - not marked as such on this map - onto the white road, Whisby Road, and immediately turn left at another new roundabout onto the Industrial Estate and again first left onto Runcorn Road, drive to the end and entrance to both the Ibis Hotel and the Pride of Lincoln, marked as an X.

North Hykeham Memorial Hall is on the north side of the A1434 marked by an **O**



CAN ABORTIVE POLIO RESULT IN LATE EFFECTS TOO?

Tessa Jupp, RN, Polio Network of Western Australia.

<http://members.upnaway.com/~poliowa/Abortive%20Polio.html>

I have in my possession a book of my aunt who worked in the polio wards at Shenton Park in 1948.

This book "Nursing in Acute Infectious Diseases" is written by the Medical Superintendent of Fairfield Infectious Diseases Hospital in Melbourne, Dr Frank Scholes, and was first published in April 1940, revised 1945.

This is an interesting book because it was written just after the major Victorian epidemic of 1937-38, by someone in the thick of polio, so we can expect this to be accurate in detail for the time. The chapter on polio lists the symptoms experienced at onset of polio and its progress.

The commonest form, spinal, could expect -

1. Fever
2. Drowsiness
3. Irritability
4. Vomiting, constipation or diarrhoea
5. Pain - head, back of neck, spine
6. Stiffness - of back of neck then also the back
7. Sensitivity to touch or pressure
8. Weakness
9. Paralysis

Other common problems he lists included insomnia, restlessness, giddiness, retention of urine, tremor of hands, sweating, loss of appetite, fear of pain on movement

This is a typical picture of a gastro-enteritis, leading to nerve and then muscle involvement.

The Bulbar form affects the top of the spinal column and can involve polio-encephalitis. If the cranial nerves are involved there could be problems with eyes, facial muscles, tongue, swallowing, voice, heart, stomach or breathing. These are the form of polio that may result in death or iron lungs. (Amongst the 1500 we have registered in Western Australia to date, we have seen or heard of polio affecting all of these areas, including deaths from cardiac involvement. He doesn't mention ears but we have seen deafness too.) One area clearly mentioned is bowel and urinary dysfunction that is not often acknowledged.

Dr Scholes also talks about subclinical polio, making the point that 90% of those with measles have symptoms, 50% of those with chickenpox, but in epidemic polio only 5% display symptoms.

So he lists 5 categories of polio.

1. Acute - with extensive paralysis
2. Acute - with very slight paralysis
3. Sub-acute - viral (flu like) with no paralysis
4. Sub-acute - vague illness
5. Sub-infection - no symptoms - self immunise

So 5% of the population had 1 or 2 and 95% had 3, 4 or 5 thus gaining protection from polio. This is interesting then when compared to the work of cell biologists, Marcia Falconer & Eddie Bollenbach, Canada, 1999. Their list reads

1. Paralytic - Spinal and Bulbar (slight paralysis is not differentiated)

2. Non-paralytic - flu like with muscle irritability.
3. Abortive - flu like symptoms
4. Sub-Clinical - no symptoms.

How polio is categorised may have an effect on gaining recognition today of the late effects of polio. A history consistent with previous polio is required. This is usually assumed to include a history of paralysis. Autopsies performed on non-paralytic polios who died of other causes, showed some nerve damage consistent with paralytic polio even though none had been apparent (Howe and Bodian, 1942). And WJW Sharrard, 1955 says "damage may have been sufficient to cause weak muscles but not enough to manifest as paralysis."

Most people fronting up to doctors regarding late effects of polio, assume they have to have had original visible paralysis to qualify. The question now raised is - Can people with other categories of polio also suffer "late effects"?

Marcia Falconer in her article documents a **"typical"** presentation of **non-paralytic polio**. "As a child I was very ill with a high fever and a headache. I was hospitalised for a few days (or quarantined and not hospitalised). My mother says I was never paralysed. I had cramps and pains in my back and legs, and was very weak for some months then recovered completely and forgot all about polio. I wasn't good at sports, but then nor were lots of other people. About 10 years ago I began tripping on smooth floors and occasionally falling. Now everyday jobs like vacuuming tire me and I may have to lie down for a bit. When I am this tired I can't think straight. My legs ache after I walk a short distance and at night the muscles in them 'jump' or twitch. My feet are always cold. I have trouble climbing a flight of stairs. My legs feel weak. I saw a post polio neurologist and he says he saw no evidence that I had ever had polio and suggests my problems are arthritis or fibromyalgia."

The problem here is that the damage is unlikely to be as extensive as with paralytic polio and EMG tests can "appear" normal unless the exact area of denervation is found by the examiner. A diagnosis in this fashion assumes that late effects can only derive from motor unit abnormalities and that no other metabolic or virological problems play any role - a fact which has not yet been established. EMG testing is valuable for ruling out other neurological causes and may establish damage due to acute polio but should not be used to prove you don't have late effects of polio. Anyone having symptoms in any category from 1-4 during the time of polio epidemics can be assumed to be a possible and probable case of polio and therefore liable to late effects at some stage.

A 1951 study on twins with polio (Hemdon & Jennings) and follow-up by (Nee et al 1995) showed that 71% of the twin with polio had PPS and surprisingly 42% of the unaffected twin have also developed symptoms of PPS. Based on this study, we could assume around half of people with non-paralytic polio could develop late effects.

Polio is an enterovirus (i.e. gut virus) and other closely related strains could inflict similar damage and late effects. There are a number of strains of polio (editors note - three strains of polio) and some are less virulent than others. Virulence was usually accorded by the number of deaths occurring not on the numbers affected.

In Western Australia, our 1954 epidemic is said to be a less virulent strain because there were only 5 deaths, compared to 25 in 1948 and 15 in 1956. But, the number of notified cases for 1954 was greater - 436, compared to 1948 - 311 and 1956 - 401. As well there were probably unreported cases that were not recognised at the time or others that were deleted when paralysis did not occur.

This information on "late effects" in non-paralytic polio would suggest that siblings, friends and relatives of polio survivors, who may have been off colour around the time you got polio, should maybe wonder about late effects too, if they are experiencing fatigue, pain or weakness now. Data collection in Western Australia includes history of polio contraction, and on speaking to many of our members, a history consistent with poor immune function at the time of obvious polio is apparent with most.

Possible reasons for under-par immune function include - previous illness or vaccination, allergies, surgery, fracture, adverse exposure to the elements, exhaustion from excessive exercise (sport, work or play), pregnancy, stressful episodes in life around that time - all factors that can stress the immune system. The reason other family members were OK would have been better immune systems at the time. They probably all had polio as well, in one of the 5 listed categories.

Statistically there is a minimum of 10 non-paralytic cases of polio to every paralytic case. Polio support groups are reporting up to 10% of their members with late effect symptoms, had non paralytic polio. We could feasibly expect that around 50% of non paralytic polios could develop late effects. So does this mean that for every case of paralytic polio there could be another 5 who had non paralytic polio, out there in the community unaware that their problems now are actually caused by the late effects of polio? The mind boggles.

Marcia Falconer concludes her article with

"In the case of non-paralytic polio, some amount of damage to neurones almost certainly took place and this may be sufficient to cause PPS symptoms of new muscle weakness, fatigue and pain."

We may be well advised to look at our old friends and relatives in a new light, recommending further investigation if they are experiencing deterioration too.

This makes even more important, the work we are doing in Western Australia on carnitine levels. The reduction of red meat intake in our diet may prove detrimental to more than presently recognised polio survivors.

THE SCOOP ON POOP.

Anyone who has ever been in hospital, will remember the strange question "Have you had your bowels open today?" What business is it! - such an intimate topic - to anyone else but me?

In ancient times - when we were children - there were such things as a Saturday dose of castor oil. My mother, a nurse, was a bit more enlightened and we got milk of magnesia! People seemed to have an obsession with "being regular". Dad used "Ford Pills". If we kids were lucky we might get "laxettes" (a chocolate aperient). More recent research confirms that yes, the longer faeces remain in the gut, more water is reabsorbed making it harder to move it along. With stagnation, more toxins are produced by the bacteria in the gut and these can find their way into the body, causing more problems. So there was some wisdom in "being regular."

As a nurse, learning how to read "poop" was part of our basic training. Many diseases and other problems were portrayed in "the pot" and a nurse's duty was the inspection of a used bedpan. Many polio patients well remember the embarrassment of either constipation and/or diarrhoea that accompanied acute polio. Now we may be having problems with our nether ends again.

My husband had problems breathing if he didn't empty his bowels two or three times a day. With weak intercostal muscles from polio, he needed abdominal space for diaphragmatic breathing. He had a regime of apples and raw cabbage at certain times of the day to make him "go".

In hospital we used to use a variety of aperients, - agarol, senakot, coloxyl, durolax and glycerine suppositories, soap enemas, as well as dietary measures like hot water, prunes, allbran, figs, grapes, dried fruit, to name but a few.

CONSTIPATION - In reality, if we have sufficient Vitamin C and magnesium, we will not have any problems with our bowels, because too much of either of these (or carnitine) gives diarrhoea. So if we take supplements of both to bowel tolerance we need not ever have problems with constipation again. As well our bodies will have sufficient of both of these for healthy immune, muscular & peristaltic function. In other words, magnesium allows the gut muscles to push it along and Vit C makes it softer and hurries it along!

WATER - The other thing we need, is plenty of water to dilute the internal sewerage so it can flow. **8-10 glasses of water** - not tea or coffee or soft or hard drinks. Plain water! Granddad always had hot water to move him!

To HAVE a GOOD POOP!

1. Drink 8-10 cups of water/day - to liquefy the gut residue
2. Enough Vitamin C twice/day - to soften & keep it moving
3. Enough magnesium X 2/day - for peristalsis (gut movement)
4. Exercise - if possible

SO WHAT CAN WE LARN FROM OUR "POOP"?

A **normal stool** should be soft, may be formed, effortless to pass and should be medium to dark brown in colour - does not float - but sinks to the bottom of the toilet bowl. **Constipation** - hard pellet like stool, can be an effort or strain to pass; be painful, you can sweat or feel faint.

Diarrhoea - frequent, loose, watery stool; may have difficulty getting to the toilet in time.

SOME SIMPLE TREATMENTS - for vomiting & diarrhoea or food poisoning - boiled water only for 24 hours - may eat freshly grated apple - or sip a dessertspoon of white malt vinegar over 5 mins - or take 60ml colloidal silver once or twice a day as needed. [See editors note below]

POOP SIGNS

Bright red stool
Red streaks on stool
Pale yellow, floating
Canary yellow
Bright yellow
Green
Pale
Clay colour
Light brown
Dark brown
Black (maleana)
Jelly coating hard stool
Ribbon shaped motion
See undigested food
Floating, greasy
Loose or runny all day,
may have tummy pain
Loose for several hours
Loose, blood, mucous, pus
Pale, bulky, greasy, foul
Constipation, hard pellets

Alternating loose & hard
Tape worm
Round worm
Thread worm

CAUSES

Beetroot if eaten, or lower gut bleed
Haemorrhoids, anal fissures, cancer
Too much fat in the diet
All milk diet e.g. normal for babies
If taking Vitamin B2 or multivitamins
Gastro-enteritis or food intolerance (new bile)
Jaundice, liver disease
Lack of bile production, gall bladder
Mixed meat & veg/fruit diet
High meat diet, wine or stout
Old blood i.e. gastric bleed, iron tablets
Irritable bowel
Bowel obstruction, polyps?, cancer?
Need to chew more or avoid that food
Excess fat in diet, digestive disturbance
Gastro-enteritis, food poisoning, too much Vitamin C or magnesium
Too much carnitine
Ulcerative colitis, cancer?
Poor absorption, coeliac disease
Dehydration, iron tablets, low Vitamin C or magnesium, low fibre in diet, irritable bowel
Bowel obstruction, cancer?
Long worm - segmented, head and body
Looks like earthworm
Like white cotton pieces

POST POLIO NETWORK OF WA INC - ABN 39 052 898 141

Polio Office and Clinic at 45A Kirwan Street Floreat WA 6014

Postal Address: PO Box 257 Subiaco WA 6904, Australia

Telephone (08) 9383 9050

Email: poliowa@upnaway.com.au

[Editors note:- Remember you need to seek the advice of a health professional before you taken any medication, vitamins or minerals.]

Two more Polio Survivor's books.

Millie Malone Lill, Polio Survivor and long time PSN contact lets us know her second ebook will be available soon. Its titled, Round Pegs, Square Holes and Pigeonholes.

Her first book, **Hot Water, Orange Juice 'n' Kids**, 1999. A collection of Millie's columns from "Gleanings," the newsletter of the Nebraska Polio Survivors Association, and "Polio Perspectives," her online newsletter. Millie's unique insights about life and about disability are mixed with humor and great wit, and a spoonful of sugar that helps the medicine go down with a laugh, a knowing nod and maybe the occasional tear.



Suggested donation of \$3.99 - <http://www.postpolioinfo.com/malone.php>

Austin Macauley Publishers Ltd

Announce Publication of British Polio Survivor's Book on 2nd March 2015

Margie Anne was born in Newcastle in 1944 and caught polio at eighteen months old and still drives with hand controls.

Challenges Within Life by Margie Anne is available to buy from www.amazon.co.uk and amazon.com and all good bookshops.

ISBN 9781784554347 and 9781784554361

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[Editors note:- VAT exemption form will be sent with the batteries for signature and return.
The amps are a little higher e.g. 55 instead of 50. Our order took just 17 hours ☺]

Your Newsletter needs your stories, hints, tips and bits

A way of doing something, or aid, that helps you might help someone else. Tell us.

How about a recipe that tastes great on the lips but not on the hips.

CARERS - Are you a Carer and would like to write and tell us how we might help Carers understand what you go through helping us manage our lives.

Articles and items for Post Polio Matters

are always welcome, by post, by email and by phone if writing is not easy for you.

Deadline date for next issue is April 25th 2015

Editors Note:-

**Articles from Polio Survivors and Health Professionals
Welcome for future issues**

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Naidex

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- ◆ Furniture,
- ◆ Communication and Telecare,
- ◆ Adaptation,
- ◆ Leisure and Sports,
- ◆ Charity and Advice.

Polio Survivor Network and other Polio Survivors attend this event.

If you are going and would like to meet up with others lunchtime let us know which day you are going to attend.

Richard and I will be there on Wednesday 29th April 2015, may stay over Tuesday night but not sure yet.

.MOBILITY ROADSHOW 2015

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Excerpted from February 14th 2015**Post-polio by Jack Briggs ! Opinion - Suwannee Democrat.**

The Democrat says: We are dedicating this editorial to Jack Briggs, Suwannee County resident of the Advent Christian Village who suffered from polio. Jack has been writing to the Suwannee Democrat for some time now. His latest edition caught our attention as he pinned the following on the back of his submission:

"I am now in the Good Sams Nursing Home at the Advent Christian Village for my last days. Okay to print any of my 'One Day at a Time' flyers. I don't believe I have much time left and I am nearly to walk with the Lord", Signed, Jack Briggs.

Mr. Briggs here is your submission

"One Day at a Time" by Jack Briggs, Echoes of polio, post-polio syndrome.

Post-polio echoes documents return of an old foe, one who has once thought defeated. Polio tried to take away our spirit from all of us that it ambushed, just as it had our physical being. Now, all survivors of polio must once again fight to hold onto the lives that we have made for ourselves. Our spirits cannot be broken. We must beat post-polio

Growing older with the disabilities that some people are left with after polio is challenging on its own. For many years, we were told by so many professionals that all our difficulties of post-polio syndrome were being attributed to normal aging. As people get older, many changes in their bodies will occur even if they remain free of disease. Some of these things include less breathing capacities, increased blood pressure, cholesterol weight and blood sugar levels, stiffening joints.

New research indicates that polio survivors' anterior horn cells may have their life span shortened by increased stresses over many years. Normal healthy aging alone cannot explain post-polio syndrome.

Facing functional losses and symptoms (especially for a second time) will have psychological implications. New symptoms are linked with depression and person's attitude to controlling the world around them. The functional abilities of post polio patients with weakness are especially vulnerable as they age.

Further studies will take place with post-polio syndrome sufferers who experience severe symptoms. Early polio tradition that affected survivors was the message to forget their bout with polio, to put the past behind them and move on with their lives. The tradition of putting the painful past behind is not one that lasts a lifetime. In fact, we are now observing the emergence of late polio traditions of rehabilitation treatment that now requires people to conserve it or lose it; to slow down a bit, to make new priorities, and to stop trying to do everything. This is devastating to a use it or lose it crowd. These new directives sound like orders to stop living.

As a polio survivor, you are an expert at being a disabled person whether you know it or not. Given your new insight into these early and late-polio traditions, perhaps we can now use the life course perspective to gain insight into the shaping of our own lives and to help us answer the question, "and now what?" that faces us each morning."

http://www.suwanneedemocrat.com/opinion/post-polio-by-jack-briggs/article_1c8d62fc-b2ea-11e4-aa95-f31aa55cfe8c.html

Management Committee [Trustees] and Operations Team

Management Committee [Trustees]

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Printing and Website - Elpeeko Ltd, Lincoln.

➔ Please contact us if you would like to help with our work ➔

Membership

Full membership includes voting rights and is available to polio survivors, their partners, families and friends.

Associate membership, no voting rights, is available to patient organisations, health and social care professionals working in the interests of polio survivors £10.00 per year

Membership Fees

UK Individual - £ 12.50 per year

Associate Membership - £ 10.00 per year

Yearly fees can be paid by Standing Order.

Life membership - £ 150.00 or pay by Standing Order £ 5.00 x 30 mo.

We welcome members living in other countries and details will be sent upon request.

Please note the majority of information will be sent via the Internet.

Email:- membership@poliosurvivorsnetwork.org.uk

All Forms are available on our Website, by phoning our helpline or writing to us.

<http://www.poliosurvivorsnetwork.org.uk/joinus.html>

Donations

giftaid it

Donations, small or large, towards our work will always be gratefully received.

SEE BACK PAGE - Val Scrivener is making and selling brilliant photo greetings cards

- Some members send us a few postage stamps
- Some members take their newsletter via the internet saving us printing and posting costs.
 - Others add a donation amount to their yearly cheque, or Standing Order amount.
- Some members send us a donation with some specifying, e.g. for AGM, for Conference. Fund
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I Run with What I Have by Bonnie L Hagy.

Available on Amazon [Hilary has copy]

Richard Daggett from Southern California writes.

We lost a treasure of the disability community. Bonnie Hagy died on January 23, 2015, after a long battle with breast cancer. Bonnie was diagnosed with polio in 1953 when she was eleven. Bonnie and her mother both had polio, and both were in iron lungs. Polio left her with no use of her arms, but enough strength to operate her wheelchair with her left foot. She was able to recover some breathing capacity but, because of the late effects of polio, she again needed to use a ventilator in recent years.

The use of a ventilator did not hinder her active life. Bonnie eventually met and married her husband, Frank, who also used a

ventilator. Frank preceded her in death. Although having to use a ventilator, and getting around via a power chair, she went everywhere she wanted. With her husband, caregivers, and friends, Bonnie visited beaches, parks, and malls. Her love for her church topped her week's activities. "I cannot live in this world and confront problems without an ongoing faith," She said. "Faith gives me strength, and keeps me going in the right direction."

Bonnie was active in the early years of disability awareness, and spoke often at board meetings and public events. She was an advocate for In-Home Support Services, and other programs that allowed the disabled to remain independent. She chronicled her life with a significant disability in her autobiography, "**I Run with What I Have.**" In a 1996 interview for New Mobility she was asked about life using a ventilator. She smiled and replied, "Ohhhh ... a ventilator, an electric blanket ... what more could I want?" ISBN Number. xxyy

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[sample cards on back page in each newsletter]

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